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Fertility Education Needs and Disparities in Female Breast Cancer Patients

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June 6, 2008

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Introduction

Recent advances in the treatment of all types of cancer have improved the survival rate of cancer patients and many have the chance to resume a normal life after treatment. This is certainly true for women survivors of breast cancer. Although studies show that there are minimal effects on the offspring of cancer survivors conceived after therapy, and that a majority of post treatment pregnancies are unaffected by previous cancer treatment, some of the treatments that save patients' lives may have an effect on their fertility and, for women, whether or not they can conceive in the future.

While the majority of breast cancer patients are older women, about five percent are under age forty. One in every three thousand pregnancies is complicated by breast cancer, either during the pregnancy or in the postpartum months (Komen Statistics, 2007). Treatment with chemotherapy causes direct damage to the ovaries, with some drugs affecting fertility more than others. During treatment, a woman may have amenorrhea temporarily or may enter early onset menopause. After chemotherapy, a woman may require further hormone treatment, during which time ovulation may or may not occur, but childbearing must be delayed until these treatments are complete. If early menopause occurs, fertility is lost (Thewes, et al. 2005). Women need to be fully informed of these side effects of treatment to prepare and make informed decisions about how to proceed with treatment.

Treatment for breast cancer is particularly grueling for the patient and some health care providers are reluctant to advise pregnancy after treatment. The hormonal nature of some types of breast cancer creates a theoretical problem with pregnancy hormones and recurrence of breast cancer. While it was thought in the past that the increased level of hormones a woman experiences while pregnant could activate breast cancers that are positive for hormone receptors, this philosophy is currently being questioned. In fact, there have been no studies that show pregnancy to be detrimental in cancer survivors and, in fact, there is some evidence to

suggest that pregnancy may have a protective effect on the breast cancer survivor (Calhoun & Hansen, 2005-2006). With this knowledge, would a breast cancer survivor decide to become pregnant after breast cancer?

The purpose of this study is to determine if premenopausal breast cancer patients feel they are well informed of the risks to their fertility and future pregnancies caused by treatment. The study will also explore from where patients get their information about fertility and what percentage of patients would like to have children after treatment. It is hypothesized that less than half the patients feel fully informed of their fertility options and that a majority of patients would like to have the option of pregnancy after treatment available to them.

Literature Review

A. Breast Cancer

1. Pathophysiology

Breast cancer strikes one in eight women in their lifetime. In 2007 approximately 178,480 new cases of breast cancer were diagnosed in the United States alone. With breast cancer being the second most lethal type of cancer in women, three percent of people affected with breast cancer will die from it (Statistics, 2006). Breast cancer is a malignancy of the breast tissue, typically found in the ducts and lobules. The rate of growth and spread of malignant cells varies greatly from patient to patient; some develop distant metastases quickly and some take years for a palpable lump to form. The initial injury in breast cancer is to the DNA. There is a mutation, interaction or environmental agent that causes a change in the DNA. This change in DNA causes abnormal, uninhibited growth of the breast tissue cells (Huether & McCance, 2004).

Some people are at an increased risk of developing breast cancer because of inherited genetic alterations. The Breast Cancer-1 (BRCA-1) gene is a tumor suppressor gene and can inhibit tumor development when it's working correctly. If there is a mutation, tumor development and growth is not suppressed. Having a mutation in this gene puts a woman at a 50% to 85%

chance of developing breast cancer in her lifetime. The BRCA-2 gene mutation has similar consequences. If women are aware that they carry these genetic mutations, they may choose to have a prophylactic mastectomy or oophorectomy (Lewis, Heitkemper, & Dirksen, 2004).

2. Role of Hormones in Breast Cancer

One of the tests a woman diagnosed with breast cancer will likely undergo will be one to determine if her cancer is estrogen receptor positive. Estrogen receptors are protein molecules in cells that can become active when an estrogen molecule enters the cell. When the receptor and the estrogen molecule bind, estrogen responsive genes begin to make messenger RNA. The messenger RNA then makes proteins that guide the cell's actions. In the breast, these messages tell the tissue to proliferate. This increased level of proliferation increases the chance that a mutated cell could divide and develop into cancer. It also increases the chance that a normal cell could mutate while dividing, therefore creating a mutated cell (Estrogen Receptors, 2006).

3. Pregnancy After Breast Cancer

Since hormones play such an important role in the development and growth of breast cancer, there is some concern about how pregnancy will affect a woman who was treated for breast cancer. There is a fear that the pregnancy hormones might cause activation of distant metastases. There have not been any studies to date, however, that have found pregnancy to be hazardous to breast cancer survivors. In fact, studies have found that those survivors who did get pregnant following treatment for breast cancer had an increased chance of survival. In this study Calhoun and Hansen (2005-2006) give two explanations for the increased survival of child bearing breast cancer survivors. The first reason is called the "Healthy Mother Effect." This states that the women who feel the healthiest and have no signs of recurring cancer will be the women who try to, and do, get pregnant. This suggests that those women who do have children after treatment were the healthiest before pregnancy and hence maintain their good health afterward (Calhoun & Hansen, 2005-2006).

The second explanation the authors give to increased survival is called the “fetal antigen hypothesis.” This hypothesis states that the mother may receive protective antibodies while pregnant. This is based on the fact that the cells of the fetus and breast cancer cells share similar antigens. The antigens expressed by the fetus may activate the woman’s immune system, stimulating cellular and humoral responses against breast cancer. This would also help to explain why there isn’t an increased rate of cancer recurrence after exposure to high levels of pregnancy hormones in this population (Calhoun & Hansen, 2005-2006).

B. Treatments

1. Fertility

Women diagnosed with breast cancer at a younger age often have a different clinical picture at the time of diagnosis. It is more likely that the cancer will be more advanced and at a later stage upon diagnosis (reference). In addition, the majority of younger women with breast cancer have tumors that are estrogen receptor negative, a prospect that limits treatment options. However, younger women often respond better to chemotherapy than older breast cancer patients, so most treatments include chemotherapy, even for early-stage tumors (Duffy, Allen, & Clark, 2006). As a result of chemotherapy, temporary or permanent menopause may occur. The type of chemotherapy drugs used and the woman’s age largely determine whether a woman will go through therapy-induced menopause and, if so, whether she will regain her menstrual cycle, and her fertility, after treatment (Minton & Munster, 2002).

As the national average age for childbirth continues to rise, fertility becomes even more important for the breast cancer patient. A woman at age 30 who receives chemotherapy is unlikely to lose her fertility due to treatment, but at age 35 there is an 18% chance that fertility will be lost. At age 40, women have a 40% chance of having permanent menopause due to treatment. Even if the woman does regain fertility, the chance she will experience premature menopause is much higher than for the general population (Brennan et al, 2005).

2. Effect on Offspring

In a study by Fossa, et al (2005), the outcomes of pregnancy and perinatal health in offspring of cancer survivors were studied. Three databases were linked to get a sample size of 13,817 subjects with a history of an invasive malignancy and in the age range of 15 to 45 at the time of diagnosis. All pregnancies that occurred nine months after diagnosis were included, which included 433 women who successfully had a total of 678 children after the cancer diagnosis. For females, the 10-year probability of post-diagnosis pregnancy was 9%, except for women with choriocarcinoma, who had a 50% probability of pregnancy post-diagnosis. The mean age for delivery of post-diagnosis children was 29.8 years for females, compared to the control population, in which the mean maternal age was 26.8 years. In the post-diagnosis group there were significantly more twins and triplets born, with the incidence of multiple births increasing in 1991 to 1998 (Fossa et al, 2005).

In comparison to the control group, the female cancer patients had more caesarean section deliveries, even when multiple births were excluded, but this statistic has decreased steadily over the years of the study. This study did not find any increase in congenital malformations in offspring of cancer patients. While there was no increase in perinatal mortality, the post-diagnosis group did have more pre-term births. On average, the cancer patients' children had a 6 day shorter gestations, which is an insignificant amount of time in a near full term pregnancy. The female cancer survivors' children also weighed an average of 130 grams less at birth. This study was cross-sectional and doesn't take into account the birth weight of siblings or congenital malformations diagnosed later in life. The results of this study show that post-diagnosis pregnancy, overall, is possible and safe for mother and baby (Fossa, et al., 2005). Good!

After overcoming cancer and the related treatment, do survivors still want to have children? In a study by Schover (2005), it was found that 60% of cancer survivors would want to have children even if they die prematurely. Ninety four percent reported that they felt well enough to have children, and 70% felt that experiencing cancer would make them a better

parent. The participants in this study were 43 men and 83 women from the Tumor Registry at the Cleveland Clinic Foundation. The criteria for the study included a diagnosis of cancer before age 35 and a minimum current age of 14 and all participants had to be disease free at the last check-up. This study did include patients with several types of cancer, so these results are not specific to breast cancer patients (Schover, 2005). If it is safe to conceive after cancer treatment and a large number of patients desire children, health care providers may need to consider a treatment plan that has less chance of causing loss of fertility and to more thoroughly discuss these topics with patients.

C. Patient Education

1. Educational Needs

In a study by Duffy, Allen and Clark (2005), young women with a breast cancer diagnosis were questioned regarding reproductive health counseling. The study included 164 premenopausal women under age 45 who were recruited from oncology offices and were beginning their first round of chemotherapy. The women were participants in a randomized controlled trial aimed at stress reduction. Telephone interviews were conducted in which the women reported what fertility topics were discussed with different doctors. The interviews were conducted on average 3.7 weeks after receiving their first chemotherapy treatment. The demographics of the women found that the majority were white, married, had children and had a household income of greater than \$60,000. The median number of physicians consulted by the patients for their cancer care was four (Duffy, Allen and Clark, 2005).

The results of the study showed that 68% of women did have a discussion with one of their health care providers about the possibility of early menopause as a consequence of treatment. However, only 34% of the participants reported that they had a discussion with their health care provider about fertility, even though all the women were premenopausal. For those that did, these discussions were most often with the medical oncologist. The odds of recalling a fertility and menopause discussion were greatly increased in those women who were privately

insured and in those women receiving hormone treatment for their cancer. Odds of recalling discussions were much lower in the lower income group. The two factors that were most influential on whether or not a fertility discussion took place were having less than four physicians and women who already had children. Higher anxiety levels were also associated with decreased odds of recalling a fertility discussion. It may be women with higher anxiety have trouble remembering these discussions or it may be that the health care provider avoided having this discussion with an anxious patient (Duffy, Allen & Clark, 2005). Regardless, in a population of women that are premenopausal, a discussion about fertility and menopause would be an important part of patient education. The health care provider should take the time to ensure that the patient understands the side effects and is aware of what may happen to her body.

In a qualitative study by Thewes, Meiser, Rickard and Friedlander (2003) 24 women under age 45 at diagnosis discussed their information needs and experiences related to their breast cancer diagnosis. The women were broken into four focus groups and were also contacted by telephone for further interview. Transcripts of the focus groups were analyzed for common themes. Of the 24 women that participated, three had treatment induced menopause and eleven of the women had a temporary cease in menstruation. Some of the women described fertility as the major concern at the time of diagnosis, while others were caught up in the decisions about treatment and the shock of the diagnosis. Many of the women agreed that as the treatment continued, fertility became more of a concern. Those women who did go through menopause said that information related to menopause was important to them, even if they were not interested in further childbearing (Thewes, Meiser, Rickard & Friedlander, 2003).

Several of the women in the focus groups reported they had not received adequate information about their fertility. They felt the information came too late, if at all. Many women reported that the burden of finding information related to menopause and fertility was in their hands. Many of the women didn't even know at the time of the focus groups what their fertility

status was. One woman said that there is a “reluctance of the doctors to realize that this is a really important issue. They have their priorities in curing you but they just thought it wasn’t that important” (p. 504). A number of the women stated that they did their own research on the topics of fertility and menopause. They talked with other patients, consulted books, magazines, support groups and the internet to learn more. Since this was a small, qualitative study, the opinions and feelings of these women may not be similar to the larger population of young breast cancer patients. Larger scale studies need to be done with a wider variety of breast cancer survivors (Thewes, Meiser, Rickard & Friedlander, 2003). This study is evidence to the fact that women want more information early in the diagnosis. Since it is such an overwhelming time, there should be multiple discussions and resources given to the women if she seeks further information.

The results of these studies show that breast cancer patients do want more information about menopause and fertility during treatment. Many of these women felt under-prepared for the effects that chemotherapy had on their fertility. Several studies show that it is safe for breast cancer survivors to have children after treatment and may even have protective effects on the mother. If the woman is less than thirty-five there is a very good chance that she won’t stop menstruating during treatment, and if she does, it will most likely return after treatment. Certain chemotherapy drugs are less toxic to the ovaries than others, and there are also other treatments available to preserve ovarian function. Ensuring that women are aware of these facts is likely to improve their ability to cope with the outcomes of therapy.

With all the information about fertility and menopause available, health care providers need to know what information to tell their patient, but many questions still remain. How would women prefer to receive this information? Would they like to have a discussion with their oncologist and receive handouts, or would they prefer to see a fertility specialist concerning these issues? Are patients getting a large amount of information from sources other than their doctors? Are these reliable sources? And what are the women’s feelings about having children

after treatment? Is childbearing still a value of theirs or are they more concerned with improving their health and dealing with the cancer diagnosis? This research hopes to find answers to some of these questions for a better understanding of the educational needs of our patients.

Methods

A. Sample

The sample population for this study included women ages eighteen to fifty who reported a breast cancer diagnosis in the past ten years. Since women older than fifty years old are likely to be in natural menopause, and thus likely to have received less information regarding fertility and menopause changes with breast cancer treatment, were excluded from this study. In addition, since very few women under age eighteen are diagnosed with breast cancer, they also were excluded from the study. A survey developed to address the research questions listed above was developed by the investigator, and was placed on the Complementary Alternatives for Breast Cancer Survivors website. Thus, only women with access to a computer with internet access were able to complete the survey. Participants were recruited from multiple sources including: the Columbus Chapter of Susan G. Komen Foundation database of breast cancer patients, distribution of fliers at two Komen Columbus events, Komen Columbus volunteers who were asked to spread the word about the survey, notice of the survey on the Young Breast Cancer Survivor Coalition website, and anyone who happened to visit the website could fill out the survey.

B. Procedure

The student researcher will include the survey questions in a larger survey being done by faculty at the Ohio State University College of Nursing. The patient database from the Susan G. Komen Foundation of Columbus was used to recruit participants as well as word of mouth and survey notices on other breast cancer support sites, such as the Young Breast Cancer Survivor Coalition. The survey was located on the internet at the Complementary Alternatives for Breast Cancer Survivors website. This website contains links and information on alternative

and complementary therapies, symptom management, and survivors and co-survivors as well as the survey. Women were told the inclusion and exclusion criteria and the time commitment for completing the questionnaires. The participants were asked to answer questions regarding demographics, as well as a reproductive questionnaire and a knowledge survey. The participants also had the opportunity to sign up on a separate database to enter drawings for gifts and gift certificates ranging from \$5 to \$50 in value. During the data collection process, drawings for \$5 to \$25 prizes were held every two weeks and \$50 gift certificates will be given out at the end of data collection. Those survey participants that were listed as recruiters by other survey participants were entered into a drawing for a \$50 gift certificate.

C. Data Analysis

Descriptive statistics were compiled to describe the sample population. Satisfaction with education by the health care provider was evaluated and compared based on pregnancies, education and other demographic information. The knowledge survey was scored by number of correct answers. Women with and without children since diagnosis were compared based on demographic and knowledge variables. The student's t-test was also used to evaluate the differences between groups.

Results

A. Participation and Demographics

The survey was completed by 17 women between the ages of 33 and 53 years old. The mean age was 44.6 years old. 68.8% of the women were currently married and 31.2% were not married. 37.5% of the women had a graduate or professional degree. 31.2% had a college degree. 12.5% had some college education. 6.2% completed high school and 12.5% had less than a high school degree. Half of our participants had children at the time of the survey and all of these children were born before their breast cancer treatment. Breast cancer diagnosis occurred before age 40 in 63% of the women.

B. Findings

None of the women surveyed were asked to meet with a fertility specialist at any time throughout their treatment. 25% of the women received their fertility and menopause education information from a non-professional source, such as the internet or support groups. A significant percentage of the women reported dissatisfaction with the fertility and menopause education they received after their diagnosis (See Table 1).

Table 1.

	Very true	Somewhat True	Somewhat not true	Not true
Overall, I was satisfied with my fertility/menopause education	25%	31.2%	18.8%	25%
I had to search for information relating to fertility/menopause	18.8%	25%	12.5%	43.8%
I felt I received information at the right time	37.5%	12.5%	18.8%	31.2%
I wanted more information about fertility/menopause	18.8%	25%	18.8%	25%

The research found a positive correlation between women who said they would have like to receive more information and those women who had to ask for more information (Pearson $r = .572$, $p = .02$). For those people who had a strong desire to have children, they desired significantly more information relating to fertility and menopause ($T = -2.93$, $df = 10$, $p = .015$). There was a positive correlation with overall satisfaction in education received and how well informed the women felt (Pearson's $r = .728$, $p < .001$). There was a positive correlation between total quiz score and education attainment. The average quiz score for those women with a high school education or less was $2.8 \pm .73$ out of 6. The average quiz score for those women with more than a high school education was $3.36 \pm .54$ out of 6.

D. Discussion

This research study highlights the needs of female breast cancer patients that are not being met. The majority of women surveyed were not completely satisfied with the education they received concerning fertility and menopause. Women who have completed a high school education or less were found to have lower quiz scores. This population, in particular, should be evaluated for response to and understanding of education given. Those women who had a strong desire to have children after treatment desired significantly more information relating to fertility and menopause. Female breast cancer patients should be asked about their desire to have children before the treatment process begins. This would assist the healthcare provider in understanding the woman's needs relating to fertility education as well as the need to meet with a fertility specialist. All premenopausal women should be offered the opportunity to meet with a fertility specialist to obtain a more thorough explanation of what may happen to their fertility status as a result of treatment as well as learn about fertility options, if interested. This education will assist female breast cancer patients to anticipate and be knowledgeable about what may happen to their fertility.

Throughout patient education, the nurse or other educator should evaluate the patient for the amount of education desired. Some women may want to know quite a bit about fertility and menopause, while other women may not be concerned with these topics. Nurses should also take the opportunity to act as patient advocates and bring the issues of fertility and menopause up with female breast cancer patients before their treatment. Patients should be fully aware of the effects that treatment can have on their fertility and menopause as well as the options available to them. Nurses have a responsibility to their patients to provide this education and ensure that patients comprehend the effects of treatment.

E. Conclusion

The results of this study clearly show the need for improved education of female breast cancer patients, specifically education on fertility and menopause. Nurses have a unique opportunity to act as patient advocates and encourage female breast cancer patients to seek

out information in this area. Assisting these women in finding credible and accessible information is one way in which nurses can provide quality education to their patients. This education can be essential for women when they are returning to a more normal life after treatment concludes.

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